Workshop 4: Data to Evaluate the Cascade

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The goal of this workshop was to share data collection efforts and data sources, and strengths and limitations of those sources to evaluate the cascade of events leading to a perinatally HIV-infected child.

PRAMS Survey: South Carolina 1995-1998

John Barnhart, South Carolina Department of Health and Environmental Control

The CDC-sponsored Pregnancy Risk Assessment Monitoring System (PRAMS) is an ongoing, population-based surveillance system that was designed to identify and monitor selected self-reported maternal behaviors and experiences that occur before, during, and after pregnancy among women who deliver a live-born infant. PRAMS data from annual surveys 1995-1998 in South Carolina indicated that 51.6% to 58.9% of all women surveyed reported that someone talked with them about how to keep from getting HIV (39.6% to 46.7% of white women and 71.0% to 78.3% of black women). In this same period, 74.9% to 77.1% of all women reported that someone talked with them about getting their blood tested for HIV (70.3% to 74.0% of white women and 82.1% to 83.3% of black women). PRAMS Survey questions added for South Carolina in 2000 sought to find out whether women had a blood test for HIV at any time during their most recent pregnancy or delivery and, if not, their reasons for not having an HIV test during their pregnancy.

Provisional data from the South Carolina HIV/AIDS surveillance system were analyzed to determine time of mother's HIV diagnosis by birth year, 1994-2000. HIV-positive status was determined prior to pregnancy in 44% for those giving birth in 1994 with a fairly steady increase to 67% in 2000. HIV-positive status was determined during pregnancy for 33% of women in 1994 with a fairly steady decrease to 26% in 2000. The other significant trend showed 15% of women being diagnosed after the birth of the child in 1994, a sharp drop to 4% in 1995 and, thus far, 0% in 2000.

The Survey of Child Bearing Women (SCBW) is still conducted in South Carolina. We can compare the total number of reported births exposed to HIV by birth year from the South Carolina HIV/AIDS surveillance system with the number derived from the SCBW. These totals for the years 1994-1999 are (surveillance system data first): 99/108, 95/109, 73/91, 97/100, 110/102, and 81/106.

Trends in the prescription and use of AZT in South Carolina are encouraging. In 2000, all three arms of AZT (during pregnancy, during labor and delivery, and neonatal) were received or prescribed in 77% of births to infected mothers compared with just 18% in 1994. AZT was received during labor and delivery in 92% of births to infected mothers in 2000 compared to 26% in 1994. Neonatal AZT was prescribed in 98% of exposed infants in 2000 compared to 42% in 1994.

The rate of Cesarean section deliveries increased from 14% in 1994 to 63% in 2000.

Results of these preventive measures are evident in the number of perinatally acquired HIV/AIDS cases by birth year in South Carolina, which has decreased from 15 cases in 1994 to just 3, 5, and 4 cases in 1997, 1998, and 1999, respectively.

HIV Counseling and Testing Among Pregnant Women in New Jersey, 1999-2000

Linda Dimasi, HIV/AIDS Surveillance Unit, New Jersey Department of Health and Senior Services

Data from New Jersey's HIV/AIDS surveillance system is available for 191 HIV-infected women who gave birth in 1999, and for 139 who gave birth in 2000. Data from New Jersey's Electronic Birth Certificate (EBC) system is available for all women giving birth in1999 (>110,000) and for women giving birth during the first seven months of 2000 (>62,000). It is estimated that 275-300 HIV-infected women give birth each year in New Jersey.

Matching our two data sources has revealed the following:

- Women receiving HIV counseling during pregnancy
  - Surveillance data:
    - 1999 data: 52% counseled, 43% unknown
    - 2000 data: 70% counseled, 28% unknown
  - EBC data:
    - 1999 data: 77% counseled, 12% unknown
    - 2000 data: 81% counseled, 8% unknown

- Women receiving HIV testing during pregnancy
  - Surveillance data:
    - 1999 data: 32% tested during pregnancy, 63% prior to pregnancy
    - 2000 data: 40% tested during pregnancy, 57% prior to pregnancy
  - EBC has no information on HIV testing

- Women receiving prenatal care
  - Surveillance data:
    - 1999 data: 14% received no prenatal care, 6% had 1-2 prenatal visits, 60% had 3 or more visits, and 20% had an unknown number of visits.
    - 2000 data: 9% received no prenatal care, 2% had 1-2 prenatal visits, 32% had 3 or more visits, and 57% had an unknown number of visits.
  - EBC data:
    - 1999 data: 1% received no prenatal care, 1% had 1-2 prenatal visits, 92% had 3 or more visits, and 6% had an unknown number of visits.
    - 2000 data: 1% received no prenatal care, 1% had 1-2 prenatal visits, 93% had 3 or more visits, and 5% had an unknown number of visits.

- HIV-infected women known to be aware of their HIV serostatus
  - Surveillance data:
    - 1999 data: 95% of infected women knew their positive status by delivery
    - 2000 data: 96% of infected women knew their positive status by delivery
  - EBC has no information on HIV status.

Pediatric HIV/AIDS cases have declined from 71 (21.1% of total exposed births) in 1993 to 22 (8.0%) in 1998. Matching of birth certificates and surveillance data has identified 81 births to HIV-infected mothers not reported to the surveillance system during this period. Matching for the years 1999-2000 is

incomplete; however, data thus far indicate 9 pediatric cases in 1999 and 1 in 2000 out of total exposed births of 189 in 1999 and 140 in 2000. Six exposures have been confirmed as not being reported to the surveillance system.

Upward trends from 1993 to 2000 in ZDV during pregnancy, ZDV during delivery, and neonatal ZDV are clear. In 2000, the ZDV (PACT 076) protocol had been partly or fully implemented in about 90% of HIV-exposed births.

In New Jersey, we are also able to compare the number of children identified through the HIV/AIDS surveillance system with numbers derived from the Survey of Childbearing Women (SCBW). SCBW also documents zidovudine use.

Perinatal HIV Prevention: Assessment Tools

Aaron Roome, Department of Public Health AIDS Division, Connecticut State Department of Health

Connecticut, population 3.4 million, has an annual birth cohort of 43,000. It is estimated there are 65-75 perinatal HIV exposures per year (1.6 per 1000 births) and 2 infections per year (about 3% of exposed–1997-1999 data). HIV infection is reportable by name for children less than 13 years old; perinatal HIV exposure is reportable as of 2001, and HIV in adults is reportable without identifiers.

Under Connecticut statutes and regulations, the health department is given broad powers to investigate reportable diseases and institute special disease surveillance as may assist it in establishing adequate control measures. Under Connecticut legislation implemented in October 1999, all pregnant women of unknown HIV status are offered an HIV test. If the woman refuses, HIV testing is mandatory for the newborn.

Outcome measures for assessing perinatal HIV prevention include: (for the population of all pregnant women) the adequacy of prenatal care and the extent of prenatal HIV testing. For HIV-positive women, outcome measures for assessing prevention include: the extent of testing during pregnancy; treatment during pregnancy, labor, and of newborns and infants; the practice of breast- feeding; and testing of exposed infants. Sources of data for the assessment of perinatal HIV transmission include the following activities by the health department's perinatal prevention program: surveillance, medical records review, birth records (includes a check box for maternal HIV), surveys of obstetricians, and audits of prenatal records. Non-health department sources include medical records reviews and interviews with women. A sampling of these data sources follows.

Vital records data for 1998 indicate that black (21%) and Hispanic (22%) pregnant women are most likely to have late or no prenatal care in Connecticut. Researchers interviewed women who had recently delivered in 1997; results published in *Obstetrics and Gynecology* (2001;97:70-6) showed that in New Haven, although 86% received information on HIV testing and 82% were offered a test, only 45% were actually tested.

An audit of prenatal/obstetric records compared percentage of pregnant women tested for HIV in 1996 (26%) to those tested in 1999 (by month of delivery). Testing increased dramatically in the last 3 months of the year (79%, 73%, and 91%), which coincided with the implementation of the mandatory newborn testing law. A survey of obstetricians in 1997 and again in 2000 (preliminary results) revealed

that more than over 95% of the obstetricians interviewed had provided prenatal HIV testing to more than 3/4 of their patients. In 1997, only about 20% of the obstetricians had provided prenatal testing to more than 3/4 of their patients.

In 2000, 93% of the obstetricians interviewed said that less than 3% of their patients refused HIV testing and 88% of the obstetricians said that none of their patients delayed or interrupted prenatal care because of concerns specifically about HIV testing (4% of physicians answered that some did (8 patients) and 8% did not know). When asked about the amount of time, on average, spent on HIV counseling with each pregnant woman, 59% of the obstetricians in the 2000 survey indicated they spent less than 5 minutes, 37% spent 5-15 minutes, and 2% spent more than 15 minutes.

Connecticut conducts surveillance for perinatal HIV exposure. Active surveillance is done at pediatric clinics where a request is made for mother/infant medical records and, based on these, an enhanced perinatal surveillance form is completed. Other case finding (in order of importance) is carried out through a review of laboratory reports (on children), the birth certificate database (which has a check box for HIV), ICD9 chart reviews, SHAS interviews, and state-funded HIV counseling and testing.

Treatment with ZDV of HIV-infected women in the prenatal or labor period and of the infant in the neonatal period is also monitored. We also monitor when HIV-positive women learn their HIV status (100% of women delivering in 2000 learned of their status before (54%) or during (46%) delivery).

A final example of surveillance activities is surveillance of the rate of HIV infection in children exposed at birth. This rate has decreased sharply from 0.51 per 1000 births in 1993 to level off at 0.05 per 1000 births in 1997 through 1999.
These data suggest the following conclusions:

- HIV reporting by name, with supportive regulations, has greatly facilitated evaluation of perinatal transmission.
- Data from a variety of sources are needed to evaluate the perinatal HIV prevention cascade.
- Legislation requiring that HIV status be known during the perinatal period has resulted in almost universal HIV testing of pregnant women.

The California Prevention of Perinatal Transmission of HIV Project: Preliminary Results of Women's Questionnaires (July–October 2000)

Liz Montgomery, Department of Pediatrics, Stanford University

Preliminary results of the childbearing women's questionnaires are based on 596 responses (162 form Sacramento County, 219 from Alameda County, and 215 from San Joaquin County) of a projected 1500 total.

About 36% of the women were black, 31% were Hispanic/Latino, and 22% were white (not Hispanic). Distribution by age group was 26% (under 20), 24% (20-25), 36% (25-34), and 14% (35 or older). About 61% had a high school degree or GED, 24% had some college or an advanced degree, and less than 15% had less than a high school education.

Sixty-nine percent were insured by Medi-Cal or other government programs; 20% had an HMO paid

through her own or her partner's employer; and 6% paid for an HMO out of their own pocket. Prenatal care for 86% of the women began in the first trimester and for 11% of the women in the second trimester.

In response to the question of whether they had *ever* been tested for HIV, 88.9% said "yes" and 8.9% said "no." Ninety-five percent of the women who were offered the test accepted; 2.6% declined. However, when we asked whether the women had been *offered* an HIV test during a prenatal visit, 79.2% answered "yes" and 18.3% answered "no." Ninety percent of the women who were offered the test accepted; 8% declined.

As to why they took the test (respondents could choose more than one reason), 91% agreed with the statement "I wanted to know my HIV status for my health and the health of my baby;" 24% agreed with the statement "I didn't feel like I had a choice;" and 63% agreed with the statement "My doctor or nurse told me I should take the test."

Other reasons women gave for taking the test included:

- had sex with guys who I didn't know, was raped, partying a lot
- to be sure and safe (past drug history)
- just took all the tests offered by the doctor
- maintain my well being
- better to be safe than sorry
- sister has HIV/AIDS
- to know for sure, take test every 6 months
- was feeling tired and ill.

Of those women who declined the test (more than one reason could be chosen), nearly 49% agreed with the statement "I didn't think I could be HIV infected;" 37% with the statement "I already had an HIV test, didn't want another one;" and 6% with the statement "I didn't want to know the results." Less than 3% indicated they did not feel comfortable with the way the doctor or nurse asked them to take the test.

Other reasons for declining the test included:

- because she told me other blood tests would show that I was HIV-positive or not, so I don't need the test
- just didn't need to take it
- never knew anyone HIV-positive and don't feel at risk
- too busy indulging in substance abuse.

We plan on looking at all of these variables in more depth, stratifying for demographic characteristics. We will also analyze data *within* counties, and compare one county to other counties and the rest of the State. For example, we want to know if there is a difference in the socio-demographic characteristics of women who are *offered* a test vs. those who are *not*. And we want to know the differences between the 8% of women who are *declining* to take a test and the 90% of women who are accepting.

Los Angeles County

Toni Frederick, Pediatric HIV-Infection Reporting (PHIR), Los Angeles County Department of Health Services

In Los Angeles county, we are able to use data from the CDC-sponsored Pediatric Spectrum of Disease study to assess progress and gaps in perinatal HIV prevention in the county. The county health department also conducted a series of exit interviews with prenatal patients at public and private clinics in the county between June 2000 and January 2001 to evaluate whether perinatal HIV counseling and testing is being universally offered, as is required by law.

Data from the Pediatric Spectrum of Disease study from 1995-2000 were analyzed to determine why failures in prevention of perinatal HIV still occurred. Of 608 children born to HIV-infected mothers in the study, 10% were infected with HIV. Twenty percent of the mothers received no prenatal care; 13% were injection drug users. All three antiretroviral interventions (prenatal ZDV, ZDV during labor and delivery and neonatal ZDV) were administered to 67% of the mother-infant pairs. Seventy-four percent of the mothers received ZDV during pregnancy and 86% of infants received neonatal ZDV. As use of maternal ZDV increased over the period, rates of perinatal transmission declined. Prenatal care was highly correlated with intervention with ZDV.

Mothers of six of the 11 HIV-infected infants born between 1998 and 2000 who received care in Los Angeles county received prenatal care. Two of the infected infants were born to women who received ZDV prenatally and at labor and delivery; these cases represent treatment failure.

To evaluate whether prenatal HIV counseling and testing were being universally offered in the county, staff from the Los Angeles County Department of Health Services interviewed pregnant women after prenatal visits at public and private clinics in the county between June 2000 and January 2001.

Of those surveyed, 95% had received information about HIV and pregnancy, about one-half had received information about HIV treatment and pregnancy, and 99% had been offered an HIV test. A total of 92% accepted the test; the main reasons for refusal were that the woman had already been tested or was in a monogamous relationship. Younger women (13-19 years) were less likely to accept HIV testing than women 20 or more years of age, although statistical significance was not reached. Foreign-born women were less likely to accept HIV testing than U.S.-born women, but statistical significance was not reached. The results confirmed that, to ensure high test acceptance rates, HIV information and counseling must be an integral component of prenatal care.

On the basis of this survey and other surveys done in Los Angeles county, the following gaps in prevention of perinatal transmission were identified. For those women with prenatal care, 5%-15% were not offered testing; 8%-20% did not accept testing; others were not retested later in pregnancy; and some delivered at a different hospital (i.e., not the HIV referral hospital) where there was either no hospital policy to ask about an HIV test or AZT was unavailable. For those women with no prenatal care (7%-20% among the HIV-infected), the problem is that rapid testing of HIV infection is currently not done.

The advent of non-named (unique identifier) reporting in California will pose several challenges: a) duplication of reports within a health department (lab reports and clinician reports); b) duplication of records within the state and outside the state (patient moving, multiple sources of care); c) educating providers (monitoring of their performance, accuracy of reports); d) problems with the unique identifier itself (changing last names, errors in dates, using “0000" for social security number); e) coordination

with the PSD study (creating the unique identifier, clarifying reporting roles); f) matching babies and moms (coordination with enhanced perinatal surveillance); and g) how to address exposed babies (assign unique identifier or hold by PSD until infection status is determined).

Massachusetts

Abbie Averbach, HIV/AIDS Bureau, Massachusetts Department of Public Health
Mukachilima Chikuba, HIV/AIDS Surveillance Program, Massachusetts Department of Public Health

Abbie Averbach discussed the Medicaid Data for Perinatal HIV Prevention Project. The objective of this project is to evaluate HIV counseling and testing rates among pregnant women enrolled in Medicaid from 1999 to 2003. We are using the following algorithm for the selection of cases to be included in the project. A case is defined as a pregnant woman who did not already know her HIV status and therefore was eligible for testing during pregnancy.

The initial cut is all women currently enrolled in Medicaid in a 2-month period (November and December) for baseline year (1999) and subsequent years. From this group we will create a subset of women who delivered in those months. We will exclude women who were previously diagnosed with HIV based on ICD-10 data. Using medical care billing information going back 7 months prior to delivery and laboratory billing information going back 7 months prior to delivery, we will identify women who were tested for HIV during pregnancy. For women who have neither a medical care billing record or laboratory billing record of an HIV test, we will pull pharmacy billing records to see if any women were being prescribed drugs that would be indicative of HIV infection. Thus, the remaining subgroup is comprised of women who were not tested for HIV during their pregnancies.

Mukachilima Chikuba reported on facility-based enhanced perinatal surveillance at three hospitals. Data from the Massachusetts Pediatric Spectrum of Disease (PSD) project for the years 1996-2000 indicate the total number of births to HIV-positive pregnant women and the number of infected children in each of these years (66/8 in 1996; 79/7 in 1997; 85/6 in 1998; 77/6 in 1999, and 51/2 in 2000 –data as of February 23, 2001).

The proportion of pregnant women known to be HIV-positive, whose country of birth is outside the U.S. and U.S. Dependencies, has increased over the last two years. The proportion of babies born to HIV-positive mothers that become infected has remained fairly constant at around 8% over the period 1996-1999. Over 90% of pregnant women known to be HIV-positive received some prenatal care in each year during the period 1996-2000. Data on the 80,866 births in Massachusetts in 1999 show that 2,886 (4%) of the mothers had no or late prenatal care; 5,708 (7%) of the infants had low birth weight; 77 (1 per 1,000) of the mothers were HIV-positive and 6 of the babies (7 per 100,000) were HIV-infected. Three of the mothers of infected infants were foreign-born, one was an injecting drug user.

Surveillance program data (as of February 1, 2001) indicate that there are 3,036 women aged 13-50 living with HIV/AIDS in the state; 17% (n=527) are foreign-born. Four percent (n=123) were known to be pregnant at the time of HIV diagnosis. Injecting drug use was the primary mode of exposure in 47% of the women.

Funds for enhanced perinatal surveillance (EPS) in Massachusetts are being used to set up facility-based surveillance at three hospitals: Boston Medical Center, University of Massachusetts Memorial Hospital,

and Baystate Medical Center. The three hospitals are not representative of birthing hospitals in the state in that they are referral centers for high-risk pregnancies and the catchment population for the hospitals is generally inner-city residents with lower socio-economic status and a larger proportion of immigrants. In addition, the hospitals:

- handle 13% of all births in Massachusetts
- diagnosed 30% of all women living with HIV/AIDS
- clientele have estimated 51%, 61%, and 71% adequacy of prenatal care (defined using the Kessner Index–state average is 80%)
- have higher proportions of low birth weight babies at 11%, 10%, and 10% (state average is 7%)
- handled 41% of all births to mothers known to b HIV-positive during the period 1996-2000.

Massachusetts has a non-name HIV reporting system. So the hospitals will generate a soundex for all records reviewed for EPS. Consent is required for release of records for review. PSD project staff have agreed to administer the consent process for EPS. A birth registry match for women of reproductive age living with HIV or AIDS will be reported to the surveillance program, using unique identifiers for HIV and names for AIDS.

Using Birth Certificate Data to Evaluate Prenatal HIV Testing Rates

Cheryl Jablonski, Texas Department of Health

New legislation effective January 1996 in Texas required prenatal care providers to test pregnant women for HIV at the first prenatal visit and at delivery, unless the women refuses. Three fields were added to the birth certificate in 1996: *Mother HIV tested prenatally? Mother HIV tested at delivery? Mother received zidovudine?* A survey of private obstetricians and gynecologists concerning their prenatal HIV testing practices was conducted; 99% of 614 reported offering an HIV test to all pregnant patients.

By multiplying the number of resident births by the rate of positive HIV tests in the Survey of Childbearing Women, we can estimate the number of HIV-infected women giving birth each year in Texas for the period 1992-1997. Based on a 20-25% vertical transmission rate for HIV without therapy and an 8% rate with therapy, potential perinatal HIV cases prevented number between 36 and 60 each year during this period in Texas.

Looking at timing of HIV test and type of prenatal care provider for pregnant women in 1997, the percentage of women tested prenatally was highest for private ob/gyn's (90.0%), followed by public health clinics (83.9%) and hospital clinics (76.4%). It was lowest for midwives (59.3%) and women with no prenatal care (22.4%). When we look at women who were tested prenatally *or* perinatally, those who used midwives (78.8%) and those with no prenatal care (88.9%) were least likely to have been tested. Most likely were those attending public health clinics (97.8%), and private ob/gyn's (95.2%).

Looking at a subset of births (Harris county which includes the city of Houston) in 1999, little variation is noted in the percentage of women tested either prenatally *or* at delivery, when race and ethnicity are considered. However, only 77.4% of Hispanic women and 85.0% of African American women were tested prenatally compared with 91.9% of white women.